

Supplemental Material

Supplemental Appendix A. Final survey instrument.

Supplemental Appendix B. Demographic characteristics and time equivalences by data source and random-parameters logit and latent-class logit results

Start

Title of Research Study: Rescuing Kidneys at Risk of Discard

Consent

Investigator: Sanjay Mehrotra, PhD

Supported By: This research is supported by National Institute of Health (NIH)

Here is why you are being asked to take part in this research study

We are asking you to take part in this research study because you are:

- A kidney transplant candidate or recipient
- are 21 or older
- speak English

This is what you should know about being in a research study

- Whether or not you take part is up to you.
- You can choose not to take part. You can also agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

This is why the research is being done

The wait-list for kidney transplant is very long. Nearly 20% of kidneys donated by a deceased donor are not transplanted and are discarded. Most discarded kidneys are of marginal or nearly marginal quality. The goal of this research study is to develop an understanding of how patients make decisions about accepting offered kidneys and get patients' perspectives on how changes can be made to the current kidney allocation policies to reduce the percent of discarded kidneys.

The purpose of this study is to create a process for giving kidneys that are at a high risk of discard (meaning that they normally wouldn't be used) to patients on the waitlist who are otherwise not likely to receive a transplant.

How long will the research last?

The survey will take approximately 15 minutes.

If you say that "Yes, you want to be in this research," here is what you will do

- If you agree to be in this study, we will ask you to complete an online survey.
- The survey will ask you to decide between different deceased donor kidney offers.
- Your participation may help us to influence policies that affect transplant candidates.

If you say that you do not want to be in this research, this is what will happen

- You can decide not to participate in this research, or discontinue participation at any time, and it will not be held against you or involve any penalty or loss of benefits to which you are otherwise entitled.
- You can say "Yes," but change your mind later
- You can leave the research study at any time and it will not be held against you. You can end your participation in the study at any time. Any data collected up until that point may be used in the research.

Here is how being in this research could be bad for you

The risk of discomfort is low. Most questions are neutral. You can exit the survey at any point.

This is what will happen to the information collected for this research

- Efforts will be made to limit the use and disclosure of your personal information, including research study records, to people who have a need to review this information.
- We cannot promise complete privacy because organizations that may inspect and copy your information include the IRB and other representatives of this institution.

- Information collected from all participants will be analyzed together, and no identifying information will be used in any publication or report.
- Identifiers will be removed from your identifiable private information and could be used for future research studies or distributed to another investigator for future research studies without your additional informed consent.

Here is who you can talk to

- If you have questions, concerns, or complaints, or think the research has hurt you, you can talk to the Principal Investigator, Dr. Sanjay Mehrotra at 847 491 3155.
- This research has been reviewed and approved by an Institutional Review Board ("IRB") (STU00208614:).

You may talk to them at (312) 503-9338 or irb@northwestern.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

ConsentQ

Do you wish to participate?

- ☐ ConsentQ=1 Yes
- ☐ ConsentQ=2 No

Next

ConsentReconsider

Your opinions on this topic are very important to us. Are you sure you don't want to participate in this study?

ConsentReconsider=1

☐

I'm sure I **don't** want to participate at this time

ConsentReconsider=2

☐

I **would** like to participate in this study

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Next

0%  100%

S1

In what year were you born?

S2

Has a doctor ever told you that you have any of the following medical conditions? *(Select all that apply.)*

S2_1

Anemia

☐

S2_2

Arthritis

☐

S2_3

Cancer

☐

S2_4

Congestive heart failure (the heart does not pump as well as it should)

☐

S2_5

Diabetes

☐

S2_6

Heart disease (for example, high blood pressure or heart attack)

☐

S2_7

Migraines

☐

S2_8

Obesity

☐

S2_9

None of the above

☐

Back

Next

0%



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S3

How many kidney transplants have you had?

S3=1

None

☐

S3=2

One

☐

S3=3

Two or more

☐

S3=4

Don't know / not sure

☐

Back

Next

0%  100%

S4

In what year did you have your most recent kidney transplant?

S5

Was your most recent transplant from a living donor?

S5=1 ☐ Yes

S5=2 ☐ No

Back

Next

0%  100%

S6

Are you currently waiting for a kidney transplant?

S6=1

Yes

☐

S6=2

No

☐

S6=3

Don't know / not sure

☐

S7

Would you consider accepting a kidney from a deceased donor?

S7=1

Yes

☐

S7=2

No

☐

S7=3

Don't know / not sure

☐

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HealthSurvey

Health Survey

Thank you for your interest in this health survey. In this survey, we will ask you to consider different options for kidney transplantation. Specifically, we would like to know what you think about options to receive a kidney from a deceased donor.

Understanding your concerns is important in helping doctors and government officials make decisions affecting people like you who are living with kidney disease.

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Q1

First, Some Questions About You

Which of the following do you currently use to manage your diabetes? *(Select all that apply.)*

Q1_1

Insulin injections

☐

Q1_2

Pills

☐

Q1_3

Diet

☐

Q1_4

I don't currently manage my diabetes

☐

Back

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0%  100%

Q2

How long have you been taking insulin injections to manage your diabetes?

Q2=1

Less than 1 year

☐

Q2=2

At least 1 year, but less than 2 years

☐

Q2=3

At least 2 years, but less than 3 years

☐

Q2=4

At least 3 years, but less than 4 years

☐

Q2=5

At least 4 years, but less than 5 years

☐

Q2=6

At least 5 years, but less than 6 years

☐

Q2=7

At least 6 years, but less than 7 years

☐

Q2=8

At least 7 years, but less than 8 years

☐

Q2=9

At least 8 years, but less than 9 years

☐

Q2=10

At least 9 years, but less than 10 years

☐

Q2=11

10 years or more

☐

Back

Next

0%  100%

Q3

How long has it been since you were first waitlisted (added to the list of all the people across the country waiting for a kidney)?

Q3=1

Less than 1 year

☐

Q3=2

At least 1 year, but less than 2 years

☐

Q3=3

At least 2 years, but less than 3 years

☐

Q3=4

At least 3 years, but less than 4 years

☐

Q3=5

At least 4 years, but less than 5 years

☐

Q3=6

At least 5 years, but less than 6 years

☐

Q3=7

At least 6 years, but less than 7 years

☐

Q3=8

At least 7 years, but less than 8 years

☐

Q3=9

At least 8 years, but less than 9 years

☐

Q3=10

At least 9 years, but less than 10 years

☐

Q3=11

10 years or more

☐

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Next

0%  100%

Q4

How long were you on the waiting list before receiving your most recent transplant?

Q4=1

Less than 1 year

☐

Q4=2

At least 1 year, but less than 2 years

☐

Q4=3

At least 2 years, but less than 3 years

☐

Q4=4

At least 3 years, but less than 4 years

☐

Q4=5

At least 4 years, but less than 5 years

☐

Q4=6

At least 5 years, but less than 6 years

☐

Q4=7

At least 6 years, but less than 7 years

☐

Q4=8

At least 7 years, but less than 8 years

☐

Q4=9

At least 8 years, but less than 9 years

☐

Q4=10

At least 9 years, but less than 10 years

☐

Q4=11

10 years or more

☐

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Next

0%  100%

Q5

Are you currently on dialysis?

Q5=1

Yes

☐

Q5=2

No

☐

Back

Next

0%  100%

Q6

How long have you been on dialysis?

Q6=1

Less than 1 year

☐

Q6=2

At least 1 year, but less than 2 years

☐

Q6=3

At least 2 years, but less than 3 years

☐

Q6=4

At least 3 years, but less than 4 years

☐

Q6=5

At least 4 years, but less than 5 years

☐

Q6=6

At least 5 years, but less than 6 years

☐

Q6=7

At least 6 years, but less than 7 years

☐

Q6=8

At least 7 years, but less than 8 years

☐

Q6=9

At least 8 years, but less than 9 years

☐

Q6=10

At least 9 years, but less than 10 years

☐

Q6=11

10 years or more

☐

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Q7

Have you ever been on dialysis?

Q7=1

Yes

☐

Q7=2

No

☐

Back

Next

0%  100%

Q8

How long were you on dialysis?

Q8=1

Less than 1 year

☐

Q8=2

At least 1 year, but less than 2 years

☐

Q8=3

At least 2 years, but less than 3 years

☐

Q8=4

At least 3 years, but less than 4 years

☐

Q8=5

At least 4 years, but less than 5 years

☐

Q8=6

At least 5 years, but less than 6 years

☐

Q8=7

At least 6 years, but less than 7 years

☐

Q8=8

At least 7 years, but less than 8 years

☐

Q8=9

At least 8 years, but less than 9 years

☐

Q8=10

At least 9 years, but less than 10 years

☐

Q8=11

10 years or more

☐

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Q9

What kind of dialysis have you received? *(Select all that apply.)*

Q9_1

☐

In center hemodialysis (your dialysis treatment was administered at a facility / clinic)

Q9_2

☐

Home hemodialysis

Q9_3

☐

Peritoneal dialysis (a sterile solution runs through a tube into your abdomen)

Q9_4

☐

Don't know / not sure

Back

Next

0%  100%

Q10

How would you rate your current health?

Q10=1
☐ Excellent

Q10=2
☐ Good

Q10=3
☐ Fair

Q10=4
☐ Poor

Q11

Which of the following would best describe your ability to do activities today?

Q11=1
☐ My life is normal.

Q11=2
☐ I have health problems, but I am able to carry on with normal, daily activities.

Q11=3
☐ I am able to care for myself, but unable to carry on with normal, daily activities or do active work.

Q11=4
☐ I need occasional assistance, but I am able to care for most of my personal needs.

Q11=5
☐ I need considerable assistance and frequent medical care.

Q11=6
☐ I am completely disabled.

Q12

When you were waitlisted for a kidney transplant, did you consent to receive offers of kidneys with KDPI greater than 85?

Q12=1
☐ Yes

Q12=2
☐ No

Q12=3
☐ Don't know / not sure

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How well a kidney works after transplant surgery

How long a transplanted kidney lasts depends on many factors, including the donor's age and health. It also depends on how well the recipient takes care of the kidney. The average kidney transplanted from a deceased donor lasts about 9 years.

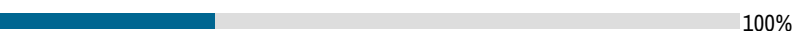
Doctors don't know exactly how well a kidney will work for you, but they do know the kinds of problems transplanted kidneys can have after surgery. This is based on their experience with many donated kidneys and from treating patients like you.

In this survey, we will ask you to consider several levels of kidney function that your doctor might expect given the quality of the kidneys they can offer. We will show you these levels in the next few screens.

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Level 1

Level 1 – Regular function after transplant

While the kidney has regular function:

- You do not need dialysis
- Your doctor may see that the kidney function is declining through blood checks or urine tests.
- You could experience some symptoms from kidney disease, like swelling of your legs, ankles, and feet.
- You could have problems with high blood pressure and experience anemia.

The symptoms are **not** severe enough to affect your ability to do daily activities (like shopping or driving).

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Level 2

Level 2 – Low function after transplant

While the kidney has low function:

- You do not need dialysis
- You may experience more severe symptoms from kidney disease, like:
 - a. Swelling of your legs, ankles, and feet
 - b. Unexplained shortness of breath
 - c. Excessive tiredness
 - d. Nausea
 - e. Loss of appetite
 - f. Numbness or tingling in the toes or fingers
 - g. Muscle cramps

The symptoms **are** severe enough to affect your ability to do daily activities (like shopping or driving), but you can still care for yourself without help.

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Level 3

Level 3 – Kidney failure

When a kidney fails, you need to go back on dialysis or get another kidney transplant.

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0%  100%

Q13

What level of kidney function...

| | Regular function | Low function |
|--|--|--|
| Did you experience after you first received your kidney? | <div>Q13_r1=1</div> <div><input type="radio"/></div> | <div>Q13_r1=2</div> <div><input type="radio"/></div> |
| Are you currently experiencing? | <div>Q13_r2=1</div> <div><input type="radio"/></div> | <div>Q13_r2=2</div> <div><input type="radio"/></div> |

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Next

0% 100%

Q14

Which of the following symptoms have you had in the last 6 months? *(Select all that apply.)*

Q14_1

Anemia

☐

Q14_2

Excessive tiredness

☐

Q14_3

High blood pressure (hypertension)

☐

Q14_4

Loss of appetite

☐

Q14_5

Muscle cramps

☐

Q14_6

Nausea

☐

Q14_7

Numbness or tingling in the toes or fingers

☐

Q14_8

Swelling of your legs, ankles, and feet

☐

Q14_9

Unexplained shortness of breath

☐

Q14_10

None of the above

☐

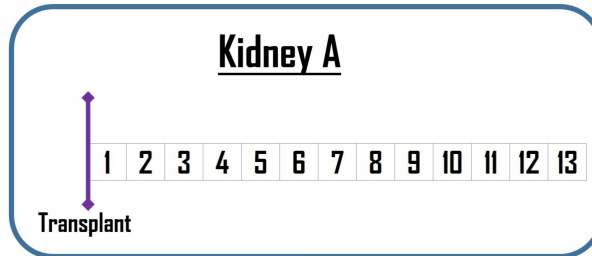
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Next

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How well a kidney could work over time

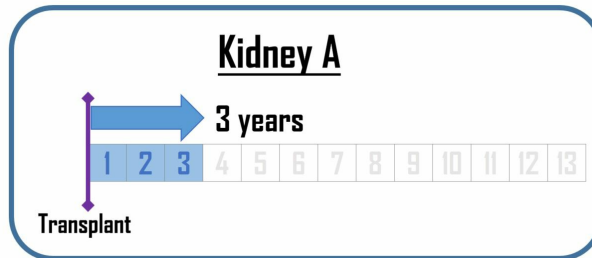
In this survey, we will use pictures like the one below to explain how long a kidney is expected to last in each level of function after transplant surgery. Each box in the picture below represents one year after Kidney A is transplanted in a patient like you.

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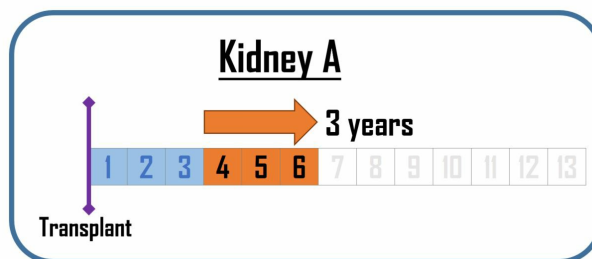
0%  100%

HowKidneyFunction2

Suppose your doctors have access to a new tool that estimates how long a kidney will maintain a specific level of function after transplant surgery if you follow their indications to take good care of the kidney and yourself. Given this information, doctors expect Kidney A will have regular function for 3 years after being transplanted. This is shown by the boxes in blue below.



After the first 3 years, Kidney A is expected to have low function for 3 years. This is shown by the boxes in orange below.



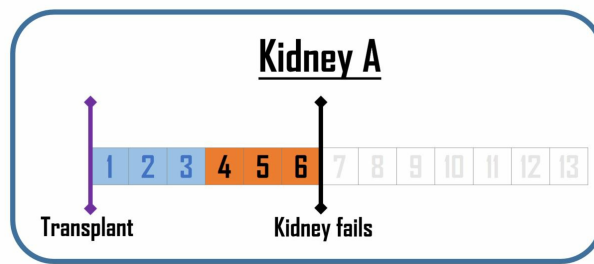
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HowKidneyFunction3

Finally, after 6 years, doctors expect Kidney A will fail, and the patient who received the kidney would have to go back on dialysis and wait for a another donor kidney.



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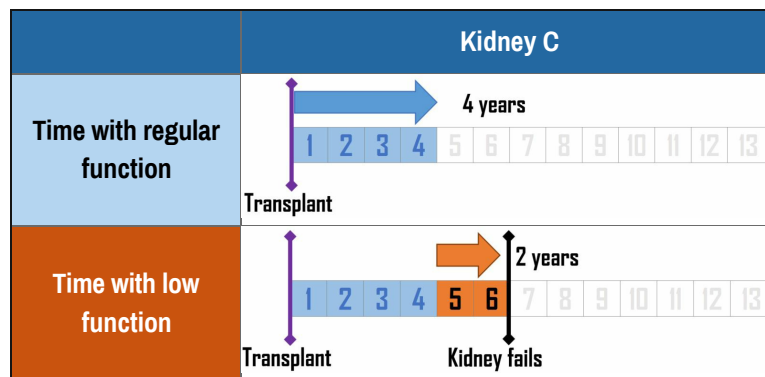
Next

0%  100%

Accepting a donated kidney

Suppose your kidney transplant starts to fail, and your doctor suggests that you get on the waitlist for another transplant. Shortly after being waitlisted, you have the opportunity to accept a kidney from a different deceased donor (Kidney C).

With the information provided by the new tool, you can see what you can expect from this kidney. The tool predicts that Kidney C will maintain regular function for 4 years and low function for 2 years.



Q15

How long will Kidney C maintain low function?

Q15=1

1 year

☐

Q15=2

2 years

☐

Q15=3

3 years

☐

Q15=4

12 years

☐

Q15=5

Don't know / not sure

☐

Q16

How long is Kidney C expected to last?

Q16=1

5 years

☐

Q16=2

6 years

☐

Q16=3

10 years

☐

Q16=4

12 years

☐

Q16=5

Don't know / not sure

☐

ReminderFlagA

[QUOTA: ReminderFlagA]

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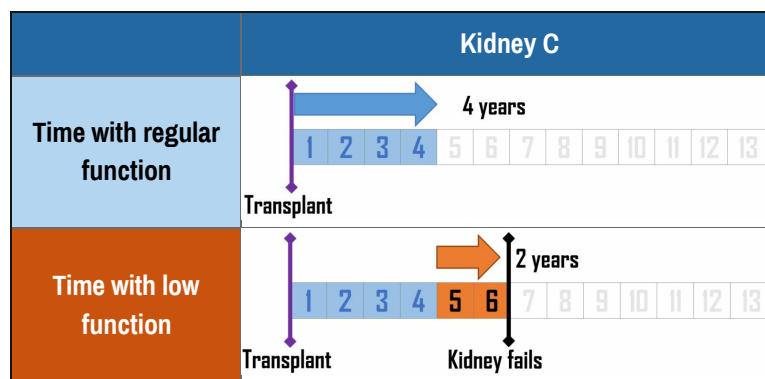
Next

0%  100%

Let's look at these questions again.

The pictures show that Kidney C will have 4 years of regular function (shown in blue). After these 4 years, the kidney is expected to have 2 years of low function (shown in orange).

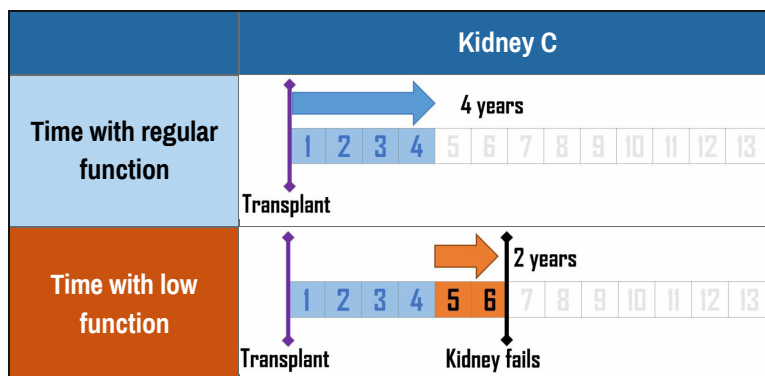
Also, Kidney C is expected to last 6 years. This is because the kidney would have 4 years of regular function plus 2 years of low function before failing.

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0% 100%

AcceptingKidneyCa1

Consider the same kidney



Q17

Would you accept Kidney C if it were available [today](#)?

Q17=1

Yes

☐

Q17=2

No

☐

Q17=3

Don't know / not sure

☐

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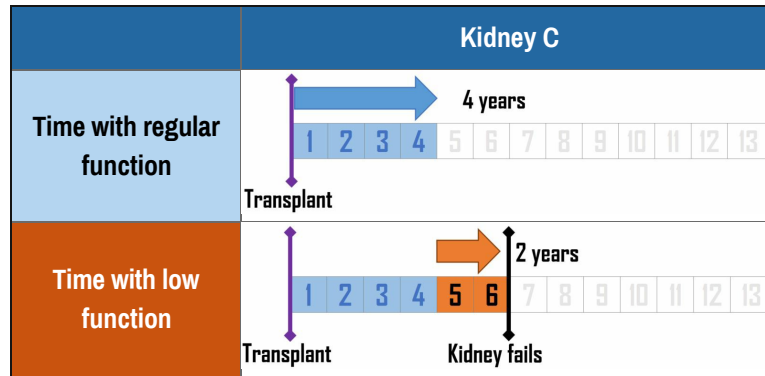
Next

0%  100%

Accepting a donated kidney

Suppose you have the opportunity to accept a kidney from a different deceased donor (Kidney C).

With the information provided by the new tool, you can see what you can expect from this kidney. The tool predicts that Kidney C will maintain regular function for 4 years and low function for 2 years.



Q15a

How long will Kidney C maintain low function?

Q15a=1

☐

1 year

Q15a=2

☐

2 years

Q15a=3

☐

3 years

Q15a=4

☐

12 years

Q15a=5

☐

Don't know / not sure

Q16a

How long is Kidney C expected to last?

Q16a=1

☐

5 years

Q16a=2

☐

6 years

Q16a=3

☐

10 years

Q16a=4

☐

12 years

Q16a=5

☐

Don't know / not sure

ReminderFlagB

[QUOTA: ReminderFlagB]

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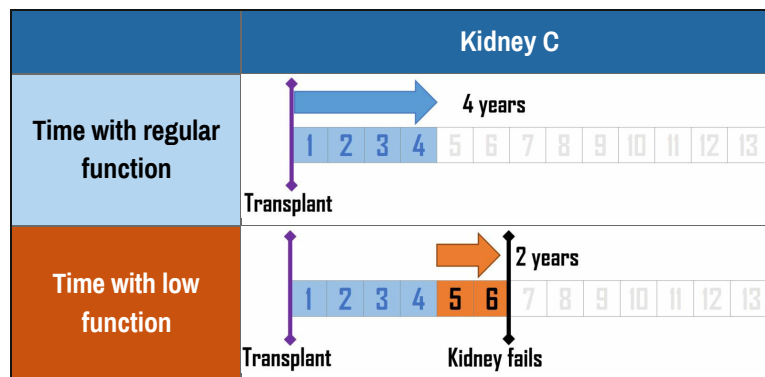


100%

Let's look at these questions again.

The pictures show that Kidney C will have 4 years of regular function (shown in blue). After these 4 years, the kidney is expected to have 2 years of low function (shown in orange).

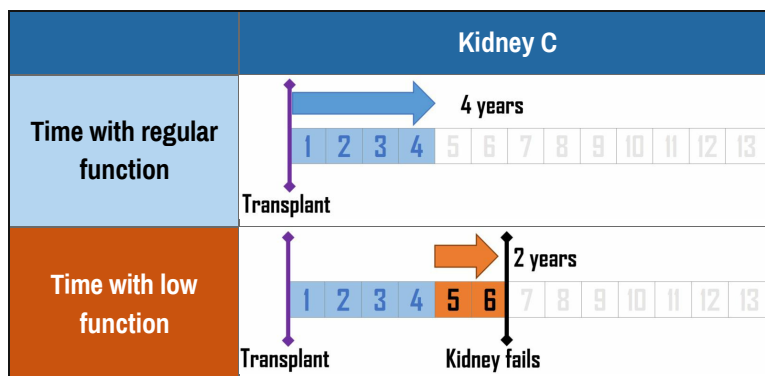
Also, Kidney C is expected to last 6 years. This is because the kidney would have 4 years of regular function plus 2 years of low function before failing.

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0% 100%

AcceptingKidneyCb1

Consider the same kidney



Q17a

Would you accept Kidney C if it were available [today](#)?

Q17a=1

Yes

☐

Q17a=2

No

☐

Q17a=3

Don't know / not sure

☐

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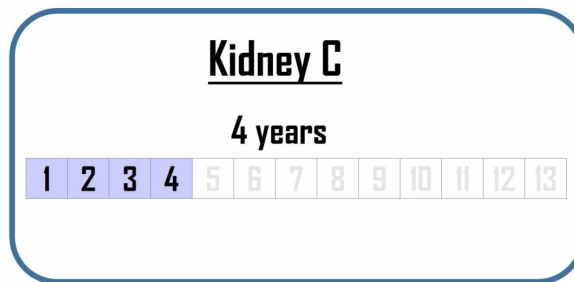
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WaitingTime

Waiting time for a donated kidney

Doctors don't know exactly how long a specific patient will have to wait for a donor kidney. However, based on their previous experience with many patients, doctors can estimate how long patients like you usually wait at their transplant center.

As before, we will use pictures to help you understand when you can expect to receive a specific kidney. The boxes in purple represent years you would have to wait to receive a donated kidney.



In this example, there are 4 boxes in purple. This means one can expect to wait 4 years to be offered Kidney C.

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Time on dialysis

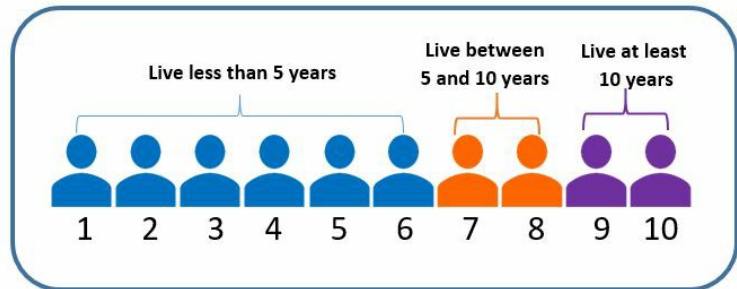
Patients usually live longer with a kidney transplant than if they remain on dialysis. How long someone can survive on dialysis depends on many factors, including the patient's age, health conditions, and adherence to the required diet and medications.

The picture below can help you think about how long patients live after starting dialysis.

- 6 out of 10 (60%) patients live less than 5 years on dialysis. These patients are shown by the blue figures in the picture.

- 2 out of 10 (20%) patients live between 5 and 10 years on dialysis. These patients are shown by the orange figures in the picture.

- 2 out of 10 (20%) patients live at least 10 years on dialysis. These patients are shown by the purple figures in the picture.

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0%  100%

Accepting a donated kidney today versus waiting for a future kidney

Suppose you have the opportunity to accept a donated kidney today. To help you consider whether you should accept this kidney, your doctor uses the tool we mentioned before and puts together the table below. The table shows the kidney offered today (**Kidney Today**), and the kidney your doctor thinks you could receive if you waited 4 more years for an offer (**Future Kidney**).

| | Kidney Today | Future Kidney |
|----------------------------|--------------------------------|------------------------|
| Time with regular function | | |
| Time with low function | | |
| Waiting time for kidney | No additional waiting time | 4 additional years |

Q18

Which kidney is expected to have more time with low function?

Q18=1

☐

Kidney Today

Q18=2

☐

Future Kidney

Q18=3

☐

Both kidneys would have the same time with low function

Q19

Which of the following options best describes what you would do in this situation?

Q19=1

☐

Accept kidney today

Q19=2

☐

Wait for future kidney

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Rampup

Consider the same kidneys

| | Kidney Today | Future Kidney |
|----------------------------|--------------------------------|------------------------|
| Time with regular function | | |
| Time with low function | | |
| Waiting time for kidney | No additional waiting time | 4 additional years |

Q20

Do you think your doctor would be worried about your chance of living long enough to receive the Future Kidney?

Q20=1

Yes

☐

Q20=2

No

☐

Q20=3

Don't know / not sure

☐

Q21

In your opinion, how likely is it that you would be offered another kidney transplant if you accepted the kidney today and it failed after 6 years?

Q21=1

Very unlikely

☐

Q21=2

Somewhat unlikely

☐

Q21=3

Somewhat likely

☐

Q21=4

Very likely

☐

Q21=5

Don't know / not sure

☐

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Accepting donated kidneys

As before, suppose your current kidney transplant starts to fail and your doctor suggests that you get on the waitlist for another transplant.

We now will ask you to consider 6 choices between pairs of kidneys. In each question, please tell us which statement would best describe what **you would do** if you could accept a kidney today or wait for a better kidney in the future. Please keep in mind that you will continue to be on dialysis as you wait for the future kidney.

There are no right or wrong answers. We are just interested in your preferences.

As you answer the questions, please assume that all costs of transplant surgery and possible complications are covered by health insurance.

Also, please assume that none of the kidneys presented come from donors who had serious infections or had lifestyle factors that put them at increased risk for serious infections (for example, HIV or Hepatitis C).

If you need to, you can refer back to any information you have reviewed as you answer the questions.

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Accepting donated kidneys

We now will ask you to consider 6 choices between pairs of kidneys. In each question, please tell us which statement would best describe what [you would do](#) if you could accept a kidney today or wait for a better kidney in the future. Please keep in mind that you will continue to be on dialysis as you wait for the future kidney.

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Also, please assume that none of the kidneys presented come from donors who had serious infections or had lifestyle factors that put them at increased risk for serious infections (for example, HIV or Hepatitis C).

If you need to, you can refer back to any information you have reviewed as you answer the questions.

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CheapTalk

We need your thoughtful answers to help us understand how you feel about donated kidneys

We need your help with a common problem we have in studies like this. Because participants do not actually have to live with the results of the decisions they report, they often do not think carefully about what they would do if they really had to make a decision.

If you do not consider the information shown in each question as you would in real life, our research findings will be wrong.

Please carefully consider the information provided in each question. Remember, there are no right or wrong answers. We are only interested in your preferences.

CVLevels

[QUOTA: CVLevels]

CVLevels2

[QUOTA: CVLevels2]

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ChoiceQuestion1

Please indicate which statement would best describe what you would do if you could accept a kidney today or wait for a better kidney in the future. In this scenario, keep in mind that you will be on dialysis as you continue to wait for the future kidney, all costs associated with the transplant are covered by insurance, and none of the kidneys are from donors with serious infectious or donors with increased infectious risk.

CQ1

| | Kidney Today | Future Kidney |
|---|--|---|
| Time with regular function | | |
| Time with low function | | |
| Waiting time for kidney | | |
| Which of the following options best describes what you would do? | <p>Choose kidney today</p> <p><input type="radio"/> CQ1_choice=1</p> <p><input type="radio"/> CQ1_choice</p> | <p>Wait for future kidney</p> <p><input type="radio"/> CQ1_choice=2</p> <p><input type="radio"/> CQ1_choice</p> |

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CQ2

| | Kidney Today | Future Kidney |
|--|---|--|
| Time with regular function | | |
| Time with low function | | |
| Waiting time for kidney | | |
| Which of the following options best describes what you would do? | <p>Choose kidney today</p> <p><input type="text" value="CQ2_choice=1"/></p> <p><input type="radio"/></p> <p><input type="text" value="CQ2_choice"/></p> | <p>Wait for future kidney</p> <p><input type="text" value="CQ2_choice=2"/></p> <p><input type="radio"/></p> <p><input type="text" value="CQ2_choice"/></p> |

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CQ3

| | Kidney Today | Future Kidney |
|--|---|--|
| Time with regular function | | |
| Time with low function | | |
| Waiting time for kidney | <p>No waiting time</p> | <p>2 additional years</p> |
| Which of the following options best describes what you would do? | <p>Choose kidney today</p> <p><input type="text" value="CQ3_choice=1"/></p> <p><input type="radio"/></p> <p><input type="text" value="CQ3_choice"/></p> | <p>Wait for future kidney</p> <p><input type="text" value="CQ3_choice=2"/></p> <p><input type="radio"/></p> <p><input type="text" value="CQ3_choice"/></p> |

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CQ4

| | Kidney Today | Future Kidney |
|--|---|--|
| Time with regular function | | |
| Time with low function | | |
| Waiting time for kidney | | |
| Which of the following options best describes what you would do? | <p>Choose kidney today</p> <p>CQ4_choice=1</p> <p><input type="radio"/></p> <p>CQ4_choice</p> | <p>Wait for future kidney</p> <p>CQ4_choice=2</p> <p><input type="radio"/></p> <p>CQ4_choice</p> |



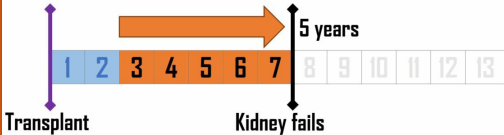
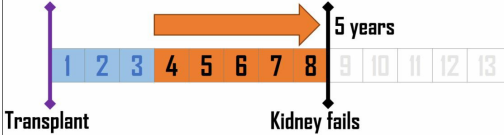


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CQ5

| | Kidney Today | Future Kidney |
|--|--|---|
| Time with regular function |  |  |
| Time with low function |  |  |
| Waiting time for kidney |  <p>No waiting time</p> |  <p>1 additional year</p> |
| Which of the following options best describes what you would do? | <p>Choose kidney today</p> <p><input type="radio"/> CQ5_choice=1</p> <p><input type="radio"/> CQ5_choice</p> | <p>Wait for future kidney</p> <p><input type="radio"/> CQ5_choice=2</p> <p><input type="radio"/> CQ5_choice</p> |

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CQ6

| | Kidney Today | Future Kidney |
|--|---|--|
| Time with regular function | | |
| Time with low function | | |
| Waiting time for kidney | <p>1 2 3 4 5 6 7 8 9 10 11 12 13</p> <p>No waiting time</p> | <p>1 2 3 4 5 6 7 8 9 10 11 12 13</p> <p>1 additional year</p> |
| Which of the following options best describes what you would do? | <p>Choose kidney today</p> <p>CQ6_choice=1</p> <p><input type="radio"/></p> <p>CQ6_choice</p> | <p>Wait for future kidney</p> <p>CQ6_choice=2</p> <p><input type="radio"/></p> <p>CQ6_choice</p> |

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AAKPIntro

So far, we have asked you to make choices based on information that your doctor would get from a tool. Such a tool does not currently exist, but we would like to understand your perspectives on how valuable such a tool would be to you.

CV1

In your opinion, would you consider this tool useful, knowing that it may only be [Script] accurate in predicting the life expediency of a deceased donor organ?

CV1=1 CV1_1_other Yes, please share why
☐

CV1=2 CV1_2_other No, please share why not
☐

CV1=3 Don't know/not sure
☐

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CV2

In your opinion, knowing that this tool may only be 70% accurate in predicting the life expediency of a deceased donor organ, how likely would you be in using the results to help inform your decision about accepting a donor kidney?

CV2=1

Very unlikely

☐

CV2=2

Unlikely

☐

CV2=3

Somewhat unlikely

☐

CV2=4

Somewhat likely

☐

CV2=5

Likely

☐

CV2=6

Very likely

☐

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CV3

As a kidney patient that has a transplant or may need a kidney transplant in the future, would you want to know a predication of life expectancy for a deceased donor organ regardless of the tools accuracy?

CV3_1_other Yes, please share why

CV3=1

☐

CV3_2_other No, please share why not

CV3=2

☐

CV3=3 Don't know/not sure

☐

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A few more questions about you

Thank you for your help with this important survey. We are almost finished. We would appreciate you sharing with us some additional information about you.

Q23

What is your gender identity?

Q23=1

Female

☐

Q23=2

Male

☐

Q23=3

Other

☐

Q23=4

Prefer not to say

☐

Q24

What is your marital status?

Q24=1

Single / never married

☐

Q24=2

Married / living as married / civil partnership

☐

Q24=3

Divorced or separated

☐

Q24=4

Widowed / surviving partner

☐

Q24=5

Other

☐[Back](#)[Next](#)

0%  100%

Q25

Which of the following racial groups best describes you? *(Select only one answer.)*

Q25=1

American Indian or Alaska Native

☐

Q25=2

Asian

☐

Q25=3

Black or African American

☐

Q25=4

Hispanic, Latino or Spanish

☐

Q25=5

Native Hawaiian or other Pacific Islander

☐

Q25=6

White or Caucasian

☐

Q25=7

Mixed race

☐

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0%  100%

Q26

What is the highest level of education you have completed? (Select only one answer.)

Q26=1

Less than high school

☐

Q26=2

Some high school

☐

Q26=3

High school or equivalent (such as GED)

☐

Q26=4

Some college but no degree

☐

Q26=5

Technical school

☐

Q26=6

Associate's degree or 2-year college degree

☐

Q26=7

4-year college degree (such as BA, BS)

☐

Q26=8

Some graduate school but no degree

☐

Q26=9

Graduate or professional degree (such as MBA, MS, MA, MD, PhD)

☐

Q27

How do you get your health insurance? (Select all that apply.)

Q27_1

Through a state or federal insurance exchange

☐

Q27_2

Through my (or another person's) employer or union

☐

Q27_3

Medicare

☐

Q27_4

Medicare Advantage

☐

Q27_5

Medicaid

☐

Q27_6

Veterans affairs / Tricare

☐

Q27_7

Federal Employee Health Benefit Program

☐

Q27_8

Other

☐

Q27_9

I do not have health insurance.

☐

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0%



100%

Q28

What was your total estimated household income before tax and other deductions in 2020? *(Select only one answer.)*

Q28=1

Less than \$25,000

☐

Q28=2

\$25,000 to \$49,999

☐

Q28=3

\$50,000 to \$74,999

☐

Q28=4

\$75,000 to \$99,999

☐

Q28=5

\$100,000 to \$149,999

☐

Q28=6

\$150,000 to \$199,999

☐

Q28=7

\$200,000 or more

☐

Q28=8

Don't know / not sure

☐

Q28=9

Prefer not to answer

☐

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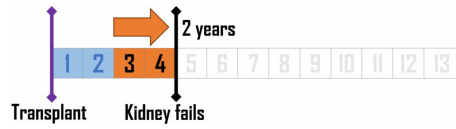
CBC_Random1

(1 of 6)

Regular function



Low function



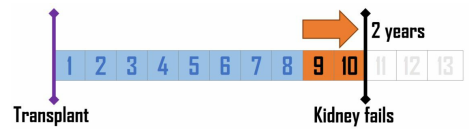
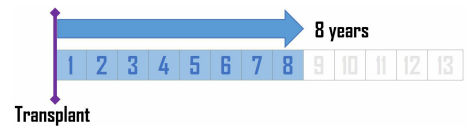
Waiting time



No waiting time

CBC_Random1

Select



5 additional years

CBC_Random1

Select

Back

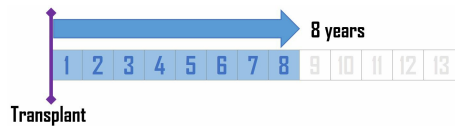
Next

0% 100%

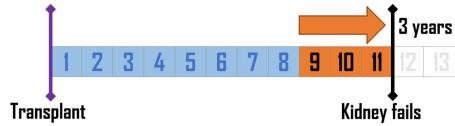
CBC_Random2

(2 of 6)

Regular function



Low function

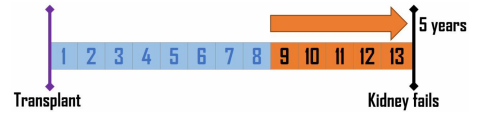
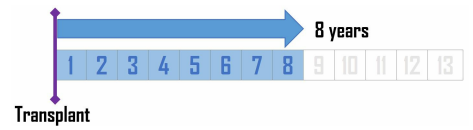


Waiting time



CBC_Random2

Select



5 additional years

CBC_Random2

Select

Back

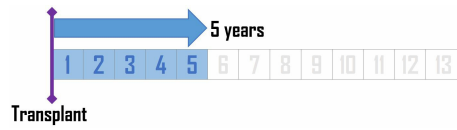
Next

0%  100%

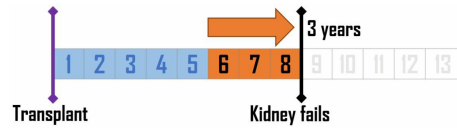
CBC_Random3

(3 of 6)

Regular function



Low function



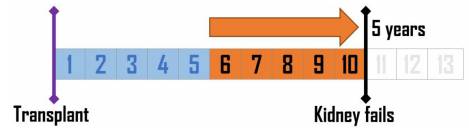
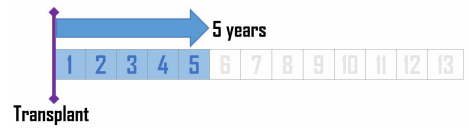
Waiting time



No waiting time

CBC_Random3

Select



2 additional years

CBC_Random3

Select

Back

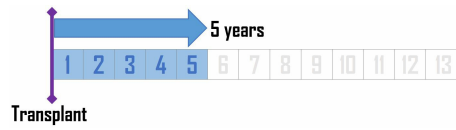
Next

0% 100%

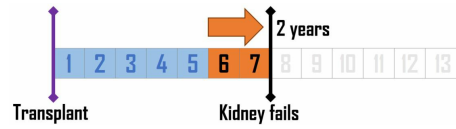
CBC_Random4

(4 of 6)

Regular function



Low function



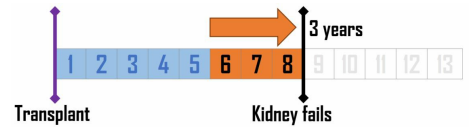
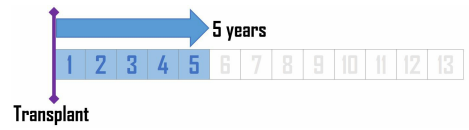
Waiting time



No waiting time

CBC_Random4

Select



2 additional years

CBC_Random4

Select

Back

Next

0%  100%

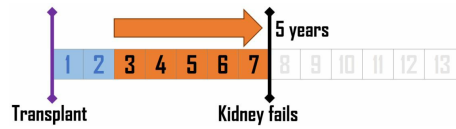
CBC_Random5

(5 of 6)

Regular function



Low function



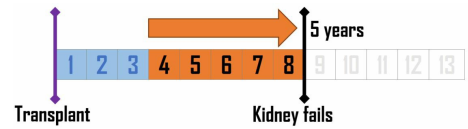
Waiting time



No waiting time

CBC_Random5

Select



1 additional year

CBC_Random5

Select

Back

Next

0%  100%

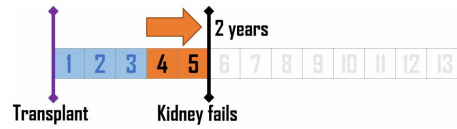
CBC_Random6

(6 of 6)

Regular function



Low function



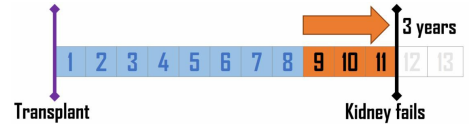
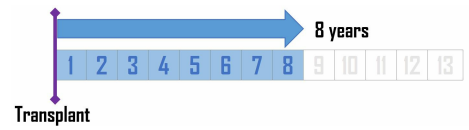
Waiting time



No waiting time

CBC_Random6

Select



1 additional year

CBC_Random6

Select

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Thank you

Thank you again for taking the time to complete this survey!

Please help us evaluate this survey by selecting what best represents your level of agreement with each of the following statements.

Evaluation

| | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|--|--|--|--|--|
| I would not recommend this survey to friends or loved ones who qualify for this study | Evaluation_r1=1 <input type="radio"/> | Evaluation_r1=2 <input type="radio"/> | Evaluation_r1=3 <input type="radio"/> | Evaluation_r1=4 <input type="radio"/> | Evaluation_r1=5 <input type="radio"/> |
| I would trust other people's kidney choices in this survey | Evaluation_r2=1 <input type="radio"/> | Evaluation_r2=2 <input type="radio"/> | Evaluation_r2=3 <input type="radio"/> | Evaluation_r2=4 <input type="radio"/> | Evaluation_r2=5 <input type="radio"/> |
| Most people probably would choose the same kidneys if they took this survey again | Evaluation_r3=1 <input type="radio"/> | Evaluation_r3=2 <input type="radio"/> | Evaluation_r3=3 <input type="radio"/> | Evaluation_r3=4 <input type="radio"/> | Evaluation_r3=5 <input type="radio"/> |
| I wanted more information to help me make choices between kidneys | Evaluation_r4=1 <input type="radio"/> | Evaluation_r4=2 <input type="radio"/> | Evaluation_r4=3 <input type="radio"/> | Evaluation_r4=4 <input type="radio"/> | Evaluation_r4=5 <input type="radio"/> |
| I carefully considered the kidney characteristics presented in the questions | Evaluation_r5=1 <input type="radio"/> | Evaluation_r5=2 <input type="radio"/> | Evaluation_r5=3 <input type="radio"/> | Evaluation_r5=4 <input type="radio"/> | Evaluation_r5=5 <input type="radio"/> |

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0% 100%

TermNonQual

Thank you so much for your interest in this survey. Unfortunately, you do not qualify to participate in the study at this time.

0%  100%

TerminateConsent

Thank you for considering this study. You have exited the survey.

0%  100%

TermFinal

Thank you again for participating in this study! You may exit the survey by closing your web browser.

0%  100%

Appendix B. Demographic Characteristics and Time Equivalences by Data Source and Random-Parameters Logit and Latent-Class Logit Results

Demographic Characteristics of Northwestern and American Association of Kidney Patient Respondents

| Demographic Characteristics | All Respondents (N=605) | Respondents from AAKP (n=409) | Respondents from Northwestern Comprehensive Transplant Center (n=196) |
|--|--------------------------------|--------------------------------------|--|
| Mean age (SD) in years | 61 (12) | 61 (12) | 61 (12) |
| Female, n (%) | 335 (56%) | 228 (56%) | 107 (55%) |
| Race, n (%) | | | |
| White or Caucasian | 458 (76%) | 309 (76%) | 149 (76%) |
| Black or African American | 84 (14%) | 55 (13%) | 29 (15%) |
| Hispanic, Latino or Spanish | 29 (5%) | 21 (5%) | 8 (4%) |
| Others | 30 (5%) | 20 (5%) | 10 (5%) |
| Missing | 4 (1%) | 4 (1%) | 0 (0%) |
| Educational attainment, n (%) | | | |
| High school or equivalent (such as GED) | 39 (6%) | 27 (7%) | 12 (6%) |
| Some college but no degree | 133 (22%) | 89 (22%) | 44 (22%) |
| Technical school, associate's degree or 2-year college degree | 83 (14%) | 54 (13%) | 29 (15%) |
| 4-year college degree (such as BA, BS) | 206 (34%) | 140 (34%) | 66 (34%) |
| Graduate or professional degree (such as MBA, MS, MA, MD, PhD) | 138 (23%) | 94 (23%) | 44 (22%) |
| Missing | 6 (10%) | 5 (1%) | 1 (1%) |
| Annual household income, n (%) | | | |
| Less than \$50,000 | 203 (34%) | 137 (33%) | 66 (34%) |
| \$50,000 to \$99,999 | 168 (28%) | 112 (27%) | 56 (29%) |
| \$100,000 or more | 131 (22%) | 92 (22%) | 39 (20%) |
| Don't know / not sure | 5 (1%) | 3 (1%) | 2 (1%) |

| | | | |
|---|-------------|-------------|-------------|
| Prefer not to answer | 92 (15%) | 60 (15%) | 32 (16%) |
| Missing | 6 (1%) | 5 (1%) | 1 (1%) |
| Clinical Characteristics | | | |
| Had diabetes, n (%) | 212 (35%) | 141 (35%) | 71 (36%) |
| Currently on dialysis, n (%) | 176 (29%) | 110 (27%) | 66 (34%) |
| Self-rating of current health, n (%) | | | |
| Excellent | 65 (10.7%) | 47 (11.5%) | 18 (9.2%) |
| Good | 335 (55.4%) | 229 (56.0%) | 106 (54.1%) |
| Fair | 188 (31.1%) | 123 (30.1%) | 65 (33.2%) |
| Poor | 17 (2.8%) | 10 (2.4%) | 7 (3.6%) |
| Self-reported performance status, n (%) | | | |
| My life is normal. | 150 (24.8%) | 106 (25.9%) | 44 (22.4%) |
| I have health problems, but I am able to carry on with normal, daily activities. | 300 (49.6%) | 202 (49.4%) | 98 (50.0%) |
| I am able to care for myself, but unable to carry on with normal, daily activities or do active work. | 95 (15.7%) | 60 (14.7%) | 35 (17.9%) |
| I need occasional assistance, but I am able to care for most of my personal needs. | 49 (8.1%) | 34 (8.3%) | 15 (7.7%) |
| I need considerable assistance and frequent medical care. | 8 (1.3%) | 5 (1.2%) | 3 (1.5%) |
| I am completely disabled. | 3 (0.5%) | 2 (0.5%) | 1 (0.5%) |
| Number of kidney transplants, n (%) | | | |
| None | 157 (26%) | 105 (26%) | 52 (27%) |
| One | 364 (60%) | 247 (60%) | 117 (60%) |
| Two or more | 84 (14%) | 57 (14%) | 27 (14%) |
| Currently waiting for a kidney transplant, n (%) | 211 (35%) | 139 (34%) | 72 (37%) |
| Average time spent waiting (SD) in years | 4 (3) | 4 (3) | 4 (3) |

| | | | |
|---|-----------|-----------|-----------|
| On waiting list for first kidney transplant and not yet on dialysis | 37 (6%) | 28 (7%) | 9 (5%) |
| Performance on Survey Questions, n (%) | | | |
| Attribute dominance | | | |
| Always chose “Kidney Today” with no waiting time | 130 (21%) | 89 (22%) | 41 (21%) |
| Always chose “Future Kidney” | 32 (5%) | 23 (6%) | 9 (5%) |
| More time with regular function | 63 (10%) | 44 (11%) | 19 (10%) |
| Less time with low function | 40 (7%) | 28 (7%) | 12 (6%) |
| Number of attribute-comprehension questions correctly answered, n (%) | | | |
| 0 or 1 | 56 (9%) | 40 (10%) | 16 (8%) |
| 2 | 97 (16%) | 63 (15%) | 34 (17%) |
| 3 | 452 (75%) | 306 (75%) | 146 (74%) |

Estimated Time Equivalences by Data Source (in Years)

| | | | Acceptable reduction in time with regular kidney function | | |
|--|---------------------------------|----|---|--------------------------------|--|
| Expected graft survival for future kidney | Reduction in total waiting time | | All Respondents (N=605)* | Respondents from AAKP (n=409)* | Respondents from Northwestern Comprehensive Transplant Center (n=196)* |
| | From | To | | | |
| 10 years including 8 years of regular function and 2 years of low function | 2 | 0 | 3.7 (3.3, 4.2) | 3.8 (3.3 ,4.3) | 3.7 (2.8, 4.5) |
| | 3 | 0 | 5.0 (4.5, 5.5) | 5.0 (4.4 ,5.6) | 5.0 (3.9, 5.7) |
| | 4 | 0 | 6.0 (5.5, 6.7) | 6.1 (5.4 ,7.3) | 5.9 (4.9, 7.1) |
| 11 years including 8 years of regular function and 3 years of low function | 2 | 0 | 4.5 (4.0, 5.1) | 4.5 (3.8 ,5.1) | 4.6 (3.8, 5.5) |
| | 3 | 0 | 5.9 (5.2, 6.6) | 5.8 (5.1 ,6.5) | 6.2 (4.6, 8.5) |
| | 4 | 0 | 7.3 (6.6, 8.5) | 7.1 (6.3 ,8.4) | 7.9 (5.9, 13.7) |
| 13 years including 8 years of regular function and 5 years of low function | 2 | 0 | 5.2 (4.6, 6.1) | 5.1 (4.4 ,6.1) | 5.6 (4.4, 7.5) |
| | 3 | 0 | 7.1 (6.2, 9.9) | 7.0 (5.9 ,10.6) | 7.5 (1.8, 17.4) |
| | 4 | 0 | 8.9 (7.5, 14.4) | 9.0 (7.3 ,16.7) | 9.4 (-3.6, 28.8) |

Random-parameters Logit Results

| Description | | Coefficient | Robust Standard Error |
|--------------------------------|----------------------------|--------------------|-----------------------|
| Regular Function (in years) | Low Function (in years) | Parameter Estimate | |
| 8 | 5 | 2.33 | 0.38 |
| 5 | 5 | 1.95 | 0.29 |
| 3 | 5 | -0.74 | 0.20 |
| 2 | 5 | -1.63 | 0.25 |
| 8 | 3 | 2.24 | 0.36 |
| 5 | 3 | 0.85 | 0.16 |
| 3 | 3 | -1.68 | 0.26 |
| 2 | 3 | -2.80 | 0.33 |
| 8 | 2 | 3.30 | 0.39 |
| 5 | 2 | 0.97 | 0.17 |
| 3 | 2 | -1.59 | 0.28 |
| Total Waiting Time (in years) | | -1.64 | 0.19 |
| Regular Function (in years) | Low Function (in years) | Standard deviation | |
| 8 | 5 | -0.73 | 0.71 |
| 5 | 5 | 0.68 | 0.44 |
| 3 | 5 | 0.03 | 0.10 |
| 2 | 5 | -1.25 | 0.36 |
| 8 | 3 | 0.97 | 0.37 |
| 5 | 3 | 0.02 | 0.05 |
| 3 | 3 | -0.08 | 0.26 |
| 2 | 3 | 0.01 | 0.13 |
| 8 | 2 | -1.21 | 0.36 |
| 5 | 2 | -1.11 | 0.33 |
| 3 | 2 | -0.78 | 0.41 |
| Total Waiting Time (in years) | | 1.40 | 0.17 |
| Log likelihood | | | -1643.87 |
| Wald chi2(12) | | | 116.25 |
| Prob > chi2 | | | 0.0000 |

Latent-Class Logit Results

| | | Class1 | | | Class2 | | | Class3 | | |
|-------------------------------|-------------------------|-------------|-----------------------|---------|-------------|-----------------------|---------|-------------|-----------------------|---------|
| Class Size | | 61% | | | 25% | | | 15% | | |
| Model for Choices | | | | | | | | | | |
| Regular Function (in years) | Low Function (in years) | Coefficient | Robust Standard Error | z-value | Coefficient | Robust Standard Error | z-value | Coefficient | Robust Standard Error | z-value |
| 8 | 5 | 2.46 | 0.23 | 10.89 | -0.85 | 0.93 | -0.91 | 7.46 | 1.54 | 4.86 |
| 5 | 5 | 1.56 | 0.19 | 8.36 | 1.54 | 0.75 | 2.06 | 1.02 | 0.86 | 1.20 |
| 3 | 5 | -0.95 | 0.19 | -5.13 | 4.02 | 1.27 | 3.17 | -1.27 | 0.58 | -2.19 |
| 2 | 5 | -1.31 | 0.19 | -7.03 | -0.79 | 0.96 | -0.83 | -2.96 | 0.56 | -5.26 |
| 8 | 3 | 1.65 | 0.21 | 7.71 | 11.81 | 2.24 | 5.28 | 7.31 | 1.16 | 6.30 |
| 5 | 3 | 0.57 | 0.12 | 4.78 | 2.41 | 0.70 | 3.46 | 0.21 | 0.72 | 0.29 |
| 3 | 3 | -1.13 | 0.17 | -6.80 | -9.11 | 1.61 | -5.67 | -3.69 | 0.76 | -4.88 |
| 2 | 3 | -2.00 | 0.17 | -11.64 | -12.11 | 1.69 | -7.19 | -5.23 | 1.21 | -4.33 |
| 8 | 2 | 2.07 | 0.17 | 12.22 | 8.08 | 1.58 | 5.11 | 8.47 | 0.91 | 9.31 |
| 5 | 2 | 0.56 | 0.15 | 3.83 | -2.34 | 0.50 | -4.65 | -0.18 | 0.47 | -0.39 |
| 3 | 2 | -1.31 | 0.17 | -7.55 | 2.43 | 1.07 | 2.27 | -4.32 | 0.94 | -4.57 |
| 2 | 2 | -2.16 | 0.20 | -10.79 | -5.09 | 1.63 | -3.11 | -6.82 | 1.34 | -5.09 |
| Total Waiting Time (in years) | | -0.84 | 0.06 | -14.27 | -10.39 | 1.19 | -8.71 | -0.11 | 0.13 | -0.86 |
| Model for Classes | | | | | | | | | | |
| Intercept | | 1.34 | 0.14 | 9.41 | 0.09 | 0.17 | 0.53 | -1.43 | 0.23 | -6.17 |
| Covariates | | | | | | | | | | |

| | | | | | | | | | |
|--|-------|------|-------|-------|------|-------|-------|----------|-------|
| ≤62/median age (vs. >62) | -0.12 | 0.17 | -0.74 | -0.85 | 0.19 | -4.46 | 0.98 | 0.25 | 3.95 |
| Black* (vs. non-Black) | -0.37 | 0.22 | -1.64 | 0.59 | 0.23 | 2.60 | -0.22 | 0.30 | -0.73 |
| No degree* (vs. having a degree) | -0.59 | 0.16 | -3.79 | 0.61 | 0.17 | 3.61 | -0.02 | 0.21 | -0.08 |
| Karnofsky score ≤60 (vs. >60) | -0.54 | 0.23 | -2.31 | 0.89 | 0.24 | 3.71 | -0.35 | 0.33 | -1.05 |
| No prior transplant, waitlisted, NOT on dialysis** | -0.22 | 0.37 | -0.58 | -1.47 | 0.57 | -2.59 | 1.69 | 0.35 | 4.81 |
| No prior transplant, waitlisted, on dialysis** | -0.20 | 0.19 | -1.03 | -0.20 | 0.21 | -0.95 | 0.40 | 0.26 | 1.53 |
| With prior transplant, waitlisted, NOT on dialysis** | -0.64 | 0.41 | -1.56 | -0.42 | 0.43 | -0.96 | 1.06 | 0.39 | 2.74 |
| With prior transplant, waitlisted, on dialysis** | 0.07 | 0.31 | 0.22 | -0.10 | 0.36 | -0.28 | 0.03 | 0.50 | 0.07 |
| With prior transplant, NOT waitlisted, on dialysis** | -0.06 | 0.34 | -0.18 | -0.49 | 0.38 | -1.29 | 0.55 | 0.43 | 1.29 |
| Log likelihood | | | | | | | | -1512.91 | |
| Bayesian information criterion | | | | | | | | 3384.50 | |
| Akaike information criterion | | | | | | | | 3137.81 | |

* Missing values were replaced by the sample means.

** Respondents who had at least one prior transplant, were not waitlisted, and were not on dialysis were the omitted category/reference group.